



The voice of those affected by cancer in Yorkshire and The Humber

## Welcome to our Winter Newsletter

Hello and lovely to catch up with everyone again.

As ever we are incredibly busy – and now we know why. Our small team of Cancer Champions has attended more than 77 events and talks this year so far, spreading the Cancer SMART message.

We also continue to run our monthly online support group – open to anyone who would like to join – usually on the second Wednesday of the month. We've had a series of fascinating and inspirational speakers including author Kevin Donaghy, patient Sandra Hudson who stays positive writing poetry and personal stylist Tammy.

For anyone who runs a patient support group, or is planning to run one, please join us for our quarterly online support group leaders' network meetings. It's good to share some of the joys and challenges of running a group.

As ever we would love to welcome more prospective trustees and Cancer Champions so if you would like to get more involved with us, please contact [info@yorkshirecancercommunity.co.uk](mailto:info@yorkshirecancercommunity.co.uk)  
Or call 07715 217845

**Best wishes**

**Jill**

## Deb Williams - a new face at SARAG (Yorkshire and Humberside Asbestos Support)

SARAG is a charity dedicated to helping people suffering from asbestos related diseases (including cancer) throughout Yorkshire, Humberside and North Nottinghamshire.

The services offered are completely free and confidential and available to anyone in the region.

They provide a wide range of specialist services including:

- Guidance on welfare benefits and compensation associated with asbestos related diseases
- Practical assistance to help complete paperwork
- Drop in session for sufferers and their families
- Monthly meetings for people affected by asbestos related diseases and their families
- A home visiting service
- Representation and support in preparing and attending formal meetings, tribunals and inquests
- Signposting to other organisations who can help

Deb is new to the Yorkshire & Humberside Asbestos Support Group team following their successful lottery funding bid.

Deb will be working with those bereaved by asbestos related disease, as well as those living with a terminal diagnosis and is available to support families and carers. You will likely meet Deb at one of SARAG's many social groups across the region but if you want to contact Deb directly, please do so on ☎ 07714172416 or ✉ [deb@saragasbestosupport.org](mailto:deb@saragasbestosupport.org).



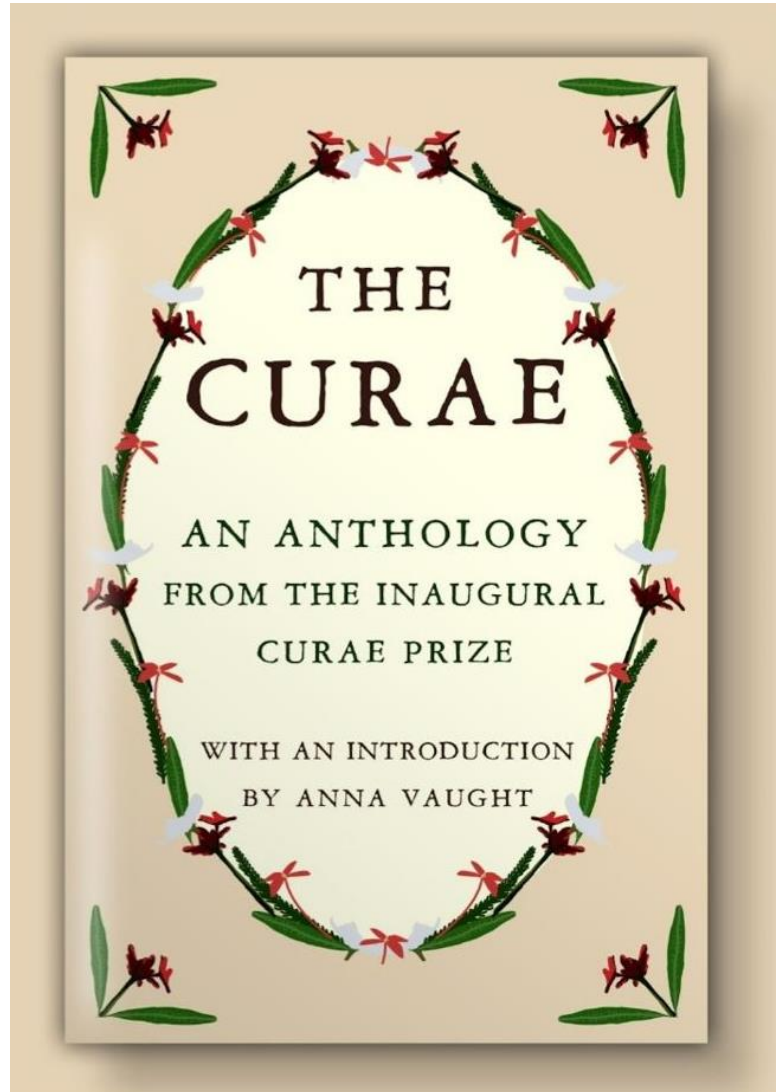


## Former cancer patient Sheena is shortlisted for a writing prize

Sheena Hussain, a former thyroid cancer patient, who left the legal profession to concentrate on her writing, has been shortlisted for the inaugural Curae Prize 2023.

Sheena who has also organised women's support groups in her home city of Bradford, has featured in our newsletter on several occasions, most recently for heading up a children's poetry competition.

It is estimated that there are around 10 million carers in the UK alone – unpaid people who look after someone who needs help because of their illness, frailty, disability, mental health problem or addiction and cannot cope without support.



The Curae Prize was established in 2022 to offer a platform to these writer-carers, offering creative focus and access to the publishing industry. Attracting a wealth of extraordinary submissions, the inaugural prize has been widely praised for its inclusivity and spotlighting of neglected talent, and this anthology celebrates the works that made it on to the shortlist.

To find out more about the anthology which features Sheena and other shortlisted entries go to: <https://renardpress.com/books/the-curae/>

To find out more about Sheena go to [www.poetrybysheenapoetrybyname.com](http://www.poetrybysheenapoetrybyname.com)

## Tammy's personal styling service – for the best version of you



Haven't we all thrown open the wardrobe door and exclaimed – but I haven't a thing to wear – while a bemused partner or friend surveys the bulging racks and shelves.

Finding the right outfit to wear for the right occasion is no easy task – but when

we're wearing our favourite dress or top – we feel a million dollars.

Our sense of confidence and self worth is all tied up in how we present ourselves to the world. Going back to an 'old favourite' that has received compliments in the past, is a safe way to go.

But for women who are either still undergoing cancer treatment, or who have just finished, the way they look can have completely changed and the old favourite outfit may no longer look suitable.

Tammy Platten ran a Hull city centre boutique for 11 years, which she had to close when she was seriously ill after having her young daughter.

To help promote her clothes, Tammy used to work with various bloggers and stylists on social media, and she realised that transferring her love of clothes from selling to styling was the way she wanted to go.

She completed a course at the London College of Style, created by industry professionals as a centre of excellence for all things fashion and now has some private clients. She may help them to shop for an outfit for a special occasion, or look at their existing wardrobe and help them work out the clothes that give them confidence.

But Tammy knew she wanted to offer the service to women who may have lost confidence because of cancer treatment or surgery. She approached Yorkshire Cancer Community for help to publicise her free service to people affected by cancer.

"When my nana was going through cancer treatment, she had her hair highlighted red and got a nose piercing. It made her happy. When my neighbour was having cancer treatment, she said she would have loved someone to help her style her clothes or go shopping with her," Tammy explained.

Our mental health has taken a beating during lockdown, and as we all stayed home, living in pyjamas or super comfortable joggers and T shirts, we lost the habit of dressing for work or pleasure.

"We're all struggling," Tammy comments. "But I feel for women who may have had a mastectomy and don't know how to dress anymore. I am qualified to help them create curves, to help them to feel confident again.

"Cancer treatment can affect a woman's skin and complexion and I want everyone to know that you don't have to be a celebrity to look good."

Tammy, a mother of two, condemns social media and some TV programmes for the unease with which some women view their bodies.

"I want to help women find their best version of themselves, to give them confidence so they value themselves again."

Tammy can offer her service to an individual or a group of ladies. To find out more contact Tammy

✉ [theredcarpet@icloud.com](mailto:theredcarpet@icloud.com)







Tammy visited the Rosewood Women's Group, Dewsbury, which is held fortnightly, to talk about how to dress to suit your shape and to present the best version of yourself. The ladies loved the session and were enthusiastically planning a clothes swap and shopping trips. Tammy can be seen third from left with members of the Rosewood and Sunovary (Ovarian Cancer Support) who joined them for the session.

A couple of quotes from happy clients:

"So date night. Going for a meal and a few rums on Humber Street. Because of you, I literally threw this on and felt great!

"Thank you so much for giving me the confidence to enjoy going out again"

"Getting you to cleanse my wardrobe and to feel confident again in clothes.... has been totally life changing. I realise who I am and how I can feel confident in my own skin and not try to be someone that I am not. I would never ever have dreamt I could have been that girl."

## Welcome Clare

After several years of working in finance and accounts, I have now joined the Yorkshire Cancer Community team as their new administrator. I am excited to start my new role, learn new skills, and most importantly to get involved in such a worthwhile cause.

Like many families, we have been directly affected by cancer several times, so it is great to have the opportunity to be able to get involved in helping cancer patients to get the support and information they need at such a challenging time.

Outside of work, I enjoy growing my own fruit and veg on my allotment, helping run a litter picking group and helping at a local animal sanctuary by doing weekend maintenance, helping at events, and running their online shop.

You'll start seeing Clare attending our events.

If you would like to get in touch, you can do so at ✉ [info@yorkshirecancercommunity.co.uk](mailto:info@yorkshirecancercommunity.co.uk)



## Wildcat Study – supporting women with endometrial cancer to be physically active

Leanne is a researcher based in Wakefield who works at the University of Leeds. Her research is around supporting women with gynaecological cancer to be physically active.

She has secured funding to involve people with lived experience of cancer in this work, and she's especially looking to involve people from diverse backgrounds.

Ideally, she hopes to offer people a guided walk, art workshop, or round-table discussion, in order to discuss the project she's designing and to better understand barriers to research amongst people from diverse backgrounds, and how they might be overcome.



Do you have personal experience of cancer? Or care for someone who does?

Are you interested in how movement can help people after cancer treatment?

I'm seeking women from ethnic minority backgrounds to shape a research project before it gets considered for funding.

Black women are especially needed due to health inequalities in this area, but all backgrounds are very welcome.

The aim is to have conversations about your experiences, barriers & motivations around research and physical activity.

I'm Leanne Shearsmith, a health researcher at the University of Leeds

I believe that research can make a difference to people with cancer and the NHS. If people from all cultures & backgrounds work together, then we can support ALL women to live better after cancer.



# WILDCAT

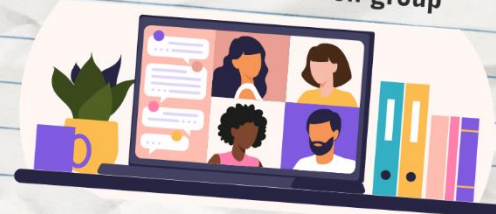
SUPPORTING WOMEN WITH ENDOMETRIAL CANCER TO BE PHYSICALLY ACTIVE

PATIENT & PUBLIC INVOLVEMENT OPPORTUNITY

Payment: £30 Amazon voucher for a 1 hour session

To share your views, you can join one of these sessions:

Online conversation group



Guided walk

Art workshop



You can also get involved by telephone or video call

Email:

[l.shearsmith@leeds.ac.uk](mailto:l.shearsmith@leeds.ac.uk)



## Mycil Muhammad – My story



When Mycil Muhammad was growing up, she always planned to write a book about her journey to the UK, leaving her sunny Caribbean home behind when she was just eleven years old.

“I’ve always been interested in Black History Month and I thought I would probably explore the huge change coming to the UK, and the life I left behind,” she explained.

In time, Mycil, who settled in Huddersfield, did write a book, but it was based on her experience of cancer.

She was diagnosed with Non-Hodgkin lymphoma – a type of cancer that affects the lymphatic system – after three years of debilitating skin conditions that were being treated with creams and steroids. She was at an all-time low, after living with an intensely itchy skin condition, which was not helped by her prescribed medication.

She went back to her very sympathetic and helpful GP and asked for a referral to Leeds, where another biopsy revealed her cancer diagnosis. It still wasn’t straight forward, as she reacted badly to chemotherapy and to the alternative drugs she was prescribed.

Over the years she battled with chronic fatigue, pain and ulcers and struggled to continue to work in various roles in the voluntary sector and with Kirklees Council.

When her Mum died in 2018, she decided to ask for her treatment to be transferred back to Huddersfield Royal Infirmary.

During Covid she worked from home but said: “I felt I was on a slippery slope in terms of my depression. I was emotionally drained and very unhappy.” Counselling and mindfulness sessions helped Mycil turn around her mental attitude. “I decided to accept the new person I had become and try to be thankful that I was still here,” she explained. “Covid was the turning point when I decided I had gone as far as I could. I hadn’t wanted to retire early but I decided to prioritise my health and took early retirement on health grounds.”

This also gave Mycil time to explore new avenues. A promotion for a coaching programme for people of colour who wanted to start their own businesses, really appealed, and she signed up.

“I didn’t know what I wanted to do, but when the other people on the course heard about my experiences, they suggested I should write a book,” Mycil recalls.

When she had been diagnosed with cancer, Mycil hadn’t been able to find any resources for talking to her children. Two from a previous relationship were grown up, but the youngest two were just starting High School. At the time her inclination was to try and protect the children, by not talking about her illness. However, because of her frequent hospital appointments and overnight stays, she realised that keeping the information to herself, was actually increasing their levels of anxiety. “My daughter was very emotional about my illness; it had a big impact on her. But as a parent, I felt I was doing the right thing, not being fully transparent.

“I hadn’t realised that my children didn’t feel they could talk openly to me. As much as you want to shield them, the best policy is to be honest and transparent.”

Mycil hopes her book, “*Having Conversations with your child about cancer*” will help open the door to those conversations, giving parents the tools they need.

The book is an activity and colouring book, that is designed to help a parent/grandparent/carer or teacher to educate your child about cancer in a simple and age-appropriate way.

Empower your child to express their emotions, ask questions and share their concerns.

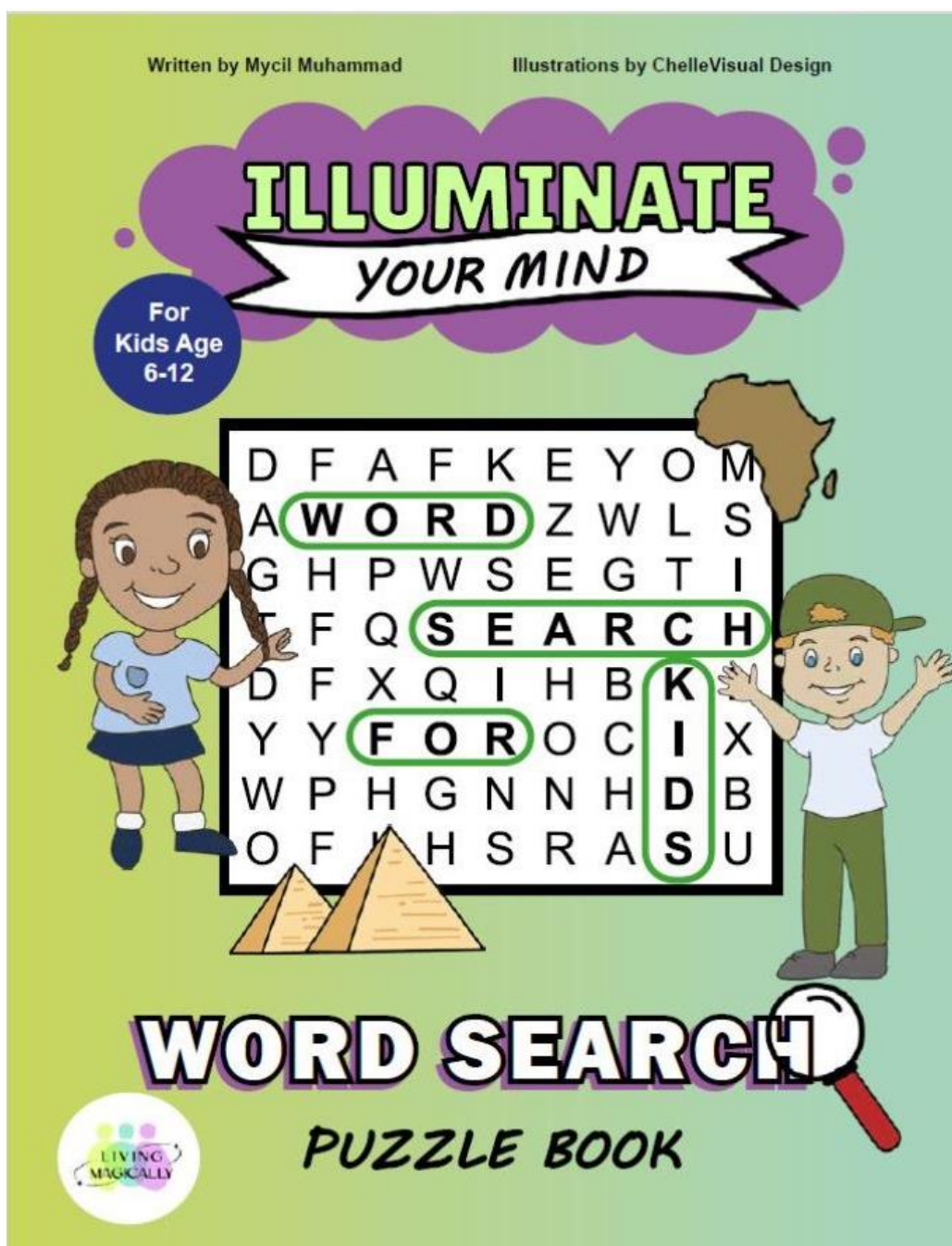
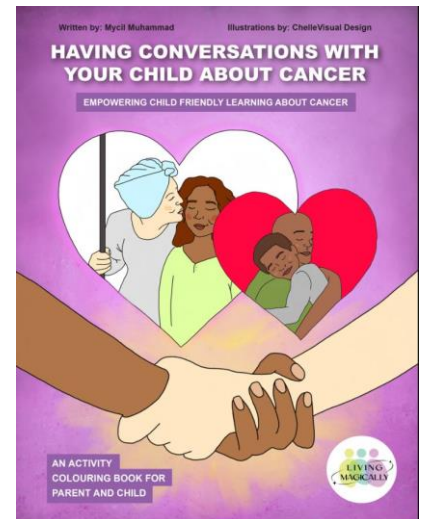
The book can be purchased on Amazon.

Mycil has created the brand, Living Magically, with plans to launch more books and online activities to support families dealing with long-term ill health, whether that be cancer, diabetes or sickle cell.

“My philosophy is also to create a safe space that will help and support our future members find meaningful solutions through sharing experiences and open discussions, Q & As and online events” she added.

Her new book, *Illuminate Your Mind*, is a wordsearch puzzle book, for children aged 6-12 years, available from Amazon.

You can get in touch with Mycil by email: [living.magicallyuk@gmail.com](mailto:living.magicallyuk@gmail.com)





## Cancer Champion Catherine updates us on her experience of thyroid cancer

Raising awareness of thyroid cancer is important to me, so when I was approached to share my story again for the newsletter, I jumped at the chance. Since I was diagnosed with thyroid cancer in 2021, I have become a little bit obsessed with checking people's necks. If anyone is on a Zoom call or I'm in a Team's meeting, by the end of it I will have studied everyone's necks for any noticeable lumps and bumps. The reason being, I didn't notice mine. In 2020 during lockdown, I was one of the unfortunate ones to catch covid at the beginning of the pandemic, I felt pretty rubbish for a long time and noticed that the glands in my neck swelled quite a lot during the time that I had it. By the summer most had gone back down, apart from one on the side of my neck, which was slightly raised. I didn't worry...my GP didn't worry, and my blood tests all came back normal so I forgot about it.

Fast forward to Christmas and I noticed again that the swelling was still visible, and I was starting to feel a slight tight feeling whenever I laid down or turned my head. Nothing uncomfortable but I just had a worry that perhaps it could be something that needed investigating further. I'd lost both my parents to cancer and my sister had just been diagnosed with breast cancer, so I knew it needed to be checked again.

This time I was fast-tracked to ENT where again I was told not to worry...it would probably be nothing but that they would check it out with an ultrasound. Anybody who has ever had to wait for an appointment, or a result will know that time seems to slow down dramatically and so the first two weeks of 2021 went by at a snail's pace. I so hoped that the consultant radiologist would find an accumulation of chocolate post-Christmas to be the cause of the swelling in my neck, but unfortunately it wasn't.

Two biopsies and a surgery four months later confirmed my worst fears, it was cancer. That word takes your breath away. In fact, it's almost not real, and trying to process that in the consultation room and on the car drive home is the strangest thing. Because life doesn't stop



when you get that diagnosis, people carry on. I still went to work, did the school run, made the dinner and cleaned the house despite my world feeling like it had exploded.

My cancer had a name Hürthle Cell Carcinoma, a rare type of Thyroid Cancer. I had already had the lump removed by the time I received my diagnosis and now needed to have the rest of my thyroid removed. So, the way I dealt with this was by reminding myself that I was already halfway through it all. The cancer had been removed and everything from now on was preventative. I was already winning this battle.

However, having your thyroid removed isn't always that straight forward. Had I known more about the thyroid and parathyroids (which sit behind the thyroid) I may have felt better prepared and have a better understanding to enable me to ask the right questions about my treatment and after-care.

The remaining thyroid was removed and my parathyroids were possibly damaged during surgery, they never recovered. I had no idea what parathyroids were (they regulate your calcium) and they were never mentioned to me, so I figured it was nothing to worry about. However, losing my thyroid and parathyroids left me with hypothyroidism and hypoparathyroidism. Meaning a lifetime of medication and a whole range of other not-so-fun symptoms.

Following radio-iodine treatment, I was given the all-clear in 2022 and a positive result in that all the cancer had been removed.

The cancer hadn't spread, and the radioiodine had been very effective; and the likelihood of it returning was minimal. People presume that the all-clear signifies getting your life back and getting back to normal, but your normal no longer exists. I would say the hardest (and longest) part of the journey was then piecing my life back together, except some of those pieces are now missing and without them things will no longer be the same and I needed to find my new normal.

Two months after the all clear I completely broke down. I felt completely alone, despite having my friends and family around me. I just didn't know how I was ever going to be able to be me again. I was trying to manage my medication, get my head around managing without my thyroid and parathyroids, be a mum, wife, friend, employee...all of it was completely overwhelming.

That's when Macmillan came in and put me on the iHope course, they got me some support and through them I discovered the Yorkshire Cancer Community and The Butterfly Thyroid Cancer Trust. The relief of meeting and talking to people who understood exactly what I was feeling was enormous. I didn't feel alone anymore, and I started to feel more confident about taking more control of my health and not being afraid to challenge people involved in my care.

Talking really does help and educating people about cancer is vital so that people can understand just how you feel and so they can help you to reach your new normal. This was really important at work, I really needed work on my side so that I could manage my symptoms and workload effectively, attend appointments and take a nap if I needed to.

People sometimes call Thyroid Cancer "the easy cancer" there is nothing easy about any cancer. However, since my diagnosis I feel more encouraged that there is more and more research and information being carried out all the time. It's becoming more widely recognised as a cancer that can affect men and women of all ages and much easier to diagnose and act upon. Even in the two years since I had my surgeries and treatment research is being carried out to look at less invasive treatments and surgeries, which is fantastic!

Thanks to the people that have helped me I've now started to find my new normal and it's going OK. Yes, I take a lot of medication, yes, I wake up each day not knowing if I am going to feel good or bad.

But less than a year on I felt well enough to take on the zipline Velocity 2 and raise almost £1k for the Butterfly Thyroid Cancer Trust and I felt amazing! I then joined the Yorkshire Cancer Community and signed up as a Cancer Champion helping to educate people in my workplace about cancer. I try to encourage people to look out for signs that something isn't right and change people's perceptions about cancer.

My aim is to help people to feel confident and supported to do something about it straight away. I now know that a cancer diagnosis isn't necessarily a death sentence and I've met some amazing people who live with cancer and enjoy life to the full who really inspire me. I would say cancer changed my life in good ways and bad, but it also gave me some precious gifts...I'm more resilient than I thought, I feel more courageous to challenge myself and take leaps and it's brought some amazing people into my life for which I am grateful.

My advice for anyone who notices anything unusual is to be proactive and get straight to the GP. In my case my only symptom was a slightly raised area on my neck...don't ignore it even if you feel well, because it could save your life and the earlier you catch it, the easier the treatment, the longer your life.

For more information, visit [butterfly: the thyroid cancer trust](#)

[The Butterfly, Me and the Big C \(butterflymeandbigc.blogspot.com\)](#)



## Yorkshire Cancer Research Centre

Yorkshire Cancer Research recently opened a new £3.5 million centre on Hornbeam Park in Harrogate. The centre is home to a specialist fitness and wellbeing programme for people with cancer, as well as a cafe, boutique-style charity shop and donation centre.



Ric, Katy and Amy in the new fitness studio

Trustee/Cancer Champion Ric Myers and myself were invited to visit and see for ourselves this wonderful facility which is just on the outskirts of the town. Ric was particularly interested to hear about the exercise programme as he has benefited in the past from a Yorkshire Cancer Research funded programme.

We were shown around by Amy Livingstone, fitness instructor and Katy Nunn, service manager.

The new centre will offer the **Active Together programme**, which aims to improve response to, and recovery from, cancer treatment. Evidence shows that exercise can improve survival and reduce the risk of cancer coming back.

Active Together offers free, personalised fitness, nutrition and wellbeing support for people following a cancer diagnosis, delivered by a team of qualified professionals.

The shop and café will help raise funds for research and services across the region, including developing more Active Together programmes which are due to start in other parts of Yorkshire.

### The benefits of Active Together for people with cancer

- Helps you recover from cancer
- Lowers the risk of cancer coming back
- Helps reduce the side effects of cancer treatment
- Boosts your mental wellbeing
- Helps other people with cancer, now and in the future



### Exercise and cancer treatment

There is growing evidence that exercise before, during and after cancer treatment can improve the effectiveness of other treatments, increase long-term survival and lower the chance of cancer coming back.

Older patients may well remember being told by their clinical staff to 'take it easy and rest up' but now patients are being advised to follow a personalised cancer exercise rehabilitation plan to help the body prepare for and recover from cancer treatment.



Watch the new Yorkshire Cancer Research film: Exercise and Cancer

[www.yorkshirecancerresearch.org.uk/exerciseandcancer](http://www.yorkshirecancerresearch.org.uk/exerciseandcancer)



When we visited, the centre was buzzing with lots of people enjoying the café and browsing around the shop.

Visitors are each received and welcomed in the reception area – a thoughtful touch – and waiting visitors are invited to enjoy the spacious contemporary surroundings while sitting on comfortable, squashy sofas surrounded by the greenery of enormous potted plants.

Amy explained that classes hadn't yet started – they were going through a 'testing' phase, but soon clients would be invited in for individual consultations to enable their own plan to be devised and delivered. On offer are also consultations with dietitians and counsellors.

People who are interested in joining the programme can contact the Active Together team directly for more information. The service is suitable for adults who are living with cancer and those who have recently had treatment. If someone has had an experience of cancer and doesn't meet this criteria, the team will help them determine what other support is available.

In the near future, Active Together programmes will be offered in other areas, using local providers, such as council-owned gyms.

If you would like to know about Yorkshire Cancer Research and what is on offer at the new centre, see [www.yorkshirecancerresearch.org.uk](http://www.yorkshirecancerresearch.org.uk)

To get in touch with the Active Together team directly, ✉ [activetogether@ycr.org.uk](mailto:activetogether@ycr.org.uk) or ☎ 01423 501 269

## My Fantastic Life with Cancer – Sandra Hudson

Sandra was one of our guests on a recent online Support Group and Chat session and everyone who attended was inspired by her positive frame of mind.

Sandra, a mother-of-two from Leeds, was diagnosed with stage 4 terminal cancer in her bowel, liver, lungs and lymph nodes in May 2017 and given just 12 months to live. Since then she's had 97 sessions of chemotherapy and a blast of radiotherapy ( as she puts it). Her dad taught her not to worry about the things she couldn't change, and having cancer is one of those.

She was in denial at first, and wanted her life to stay 'normal', by that, she meant carrying on teaching at a Morley school. The hospital suggested she should retire, and her best friend said that if she kept working, by the time she retired, she would be too poorly to do the things she wanted to do.



Sandra said that was really good advice and retired eight years early and has spent those years travelling all over the world, spending more time with her lovely family and taking up a whole host of hobbies.

During hospital stays and chemotherapy, she has always put pen to paper about her experiences, and following a turn for the worse with her health, decided to commit those poems to print form.

Fundraiser and podcaster Jacqui Drake (Jacqui's Million) helped Sandra to lay out the book and within three weeks it was ready to go.

*My Fantastic Life With Cancer* was launched on 7 October, at a party Sandra held to celebrate her life.

She believes staying positive has helped her to stay well, and staying busy, going out each day, and continuing to take an interest in life has all helped.

The proceeds from her book will go to The Morley Shed, where men and women can come together and be creative with all materials provided at a very low cost.

To order the book:

For the book and delivery, it costs £5 + £2.50 = £7.50

✉ [allison.speller@groundwork.org.uk](mailto:allison.speller@groundwork.org.uk)

☎: Ally 07971842732 or John 07870848064 who will give details of the bank transfer.

Here's one of Sandra's poems:

### **Six years of living with cancer**

Still feeling the wind and sun on my face,  
Living my best life, but at a slower pace.  
Watching another year of my children grow up,  
And still walking Teddy, as I have since he was a pup.  
All my holidays now UK bound,  
But lots of places to see, I have found.  
With my husband, Paul, we will have lots of trips,  
And on the sea front, probably eat fish and chips.

Wherever we go, we will be together,  
And have a brilliant time, no matter what the weather.  
Boat trips, coach trips, hotels by the sea,  
We will have a lovely time, just wait and see.  
Keeping busy with woodwork, in Morley at The Shed,  
It really keeps me sane and clears my head.  
French boules on a Saturday morning we play,  
Such a lovely group and a happy start to the day.  
Going to pub quizzes with my family and friends,  
A few beers and a laugh is how the night ends.  
Nights out or a coffee with my mates,  
I really enjoy our 'girlie' dates.

Whatever my future treatment brings,  
I'm sure I'll still cram in lots of things.  
Cancer might have changed my life for a long while,  
But it will never ever take away my smile.  
Carry on treatment, keep smiling through,  
It is the only thing you can really do.



## Moving Forward

We know it's not always 'back to normal' when you finish hospital treatment for primary breast cancer.

Coping with the shock of a diagnosis, treatment and side effects, and worries about recurrence can make it difficult to readjust to the everyday. Finishing treatment at your hospital can sometimes mean leaving behind the routine and support you've become used to. It may have left you feeling alone.

That's why Moving Forward is here. Through supportive, open conversations in a safe, confidential space, you'll connect with people who understand. And you'll find the tools you need to feel more empowered, confident and in control. Ready to move forward with your life. You can attend a face-to-face course or join an online course.

The courses are run in conjunction with the NHS, over 2 weeks, with 2, 3.5 hour sessions run by one of our expert facilitators. Groups are kept small, with no more than 12-15 people attending. We also have our trained volunteers on hand to welcome you and share their own experience of a breast cancer diagnosis and treatment. Everyone is encouraged to participate in a way that suits them. The course is supported by online resources and our Moving Forward journal.

**Week one:** Looking back to move forward. A chance for the group to share common ongoing concerns and discuss the impact of diagnosis and treatment.

**Online content:** Activity and energy, Mental wellbeing, Lymphoedema, Menopausal symptoms, Recurrence, Eating well and breast cancer and Adjusting and adapting

**Week two:** Setting intentions within a wellbeing framework, we look at the Five Ways to Wellbeing, and what people need to move forward. Supported by a Q&A session with a healthcare professional, and content from your Moving Forward journal.

**You can join courses in Sheffield, Barnsley, Rotherham, Doncaster, Worksop, Chesterfield, York, Scarborough, Scunthorpe, Grimsby and Northallerton.**

We also have our new online courses run over two weeks, with two three-hour sessions and are facilitated by our expert staff.



**BREAST  
CANCER  
NOW** The research  
& care charity

### What people have told us:

*'Just didn't realise how much I needed the time to be able to reflect and acknowledge what I had been through. Thank you for providing this time and expertise to help complete my cancer journey.'*

*'Excellent couple of days met fabulous people, put everything into perspective. The future looks so much brighter. Thank you'*

*'The course was fantastic, really informative especially regarding diet, exercise and lymphoedema. The whole course helped me feel more empowered and in control. The body awareness section was extremely helpful.'*

*'Hearing from others was reassuring that I wasn't alone or the only one who was scared.'*

*'I think the course would be very helpful for anyone who is anxious and frightened about their life after their breast cancer diagnosis.'*

Find a course near you or register for an online course today. [breastcancernow.org/movingforward](https://breastcancernow.org/movingforward)  
0345 077 1893 [movingforward@breastcancernow.org](mailto:movingforward@breastcancernow.org)



## Blood Cancer Open Day for Patients and Families

In October, the [Epidemiology & Cancer Statistics Group](#) (ECSG), which is based at the University of York and part of the [Centre for Blood Research](#) (CBR), had the pleasure of welcoming around 200 patients and their families and friends, as well as NHS staff, to an Open Day to share knowledge and experiences.

The event included a series of talks from haematologists, patients and researchers/scientists, as well as interactive areas and places to chat with blood cancer support groups and charities. Those attending were able to learn more about ECSG's research - which they are part of and contribute to - including the data collected and how it is used.

We then heard a patient account of his personal blood cancer journey and some of the drawbacks of treatment, which many audience members could relate to. Additional talks were given on clinical trials and childhood cancer. Links to the presentations can be found [here](#), and to the photographs [here](#).

Feedback about the Open Day was overwhelmingly 'excellent', with everyone saying they enjoyed the event, and especially the chance to learn more about blood cancer and chat to people with similar experiences, as indicated from the quotes below:

"An amazing, informative day. A great balance of research and patient views and stories."

"I came to support my friend. I left speechless. Amazing knowledge, dedication and to think this is in York. So proud of you!"

"I am so please that we have all these people who are doing what they do. Huge thanks for the chance to attend. Excellent!"

Debra Howell, who leads on Patient and Public Involvement (PPI) in ECSG said *'it was fantastic to be able to meet again with the people who are most impacted by our research. PPI is such a crucial aspect of our work; it helps us to learn about the issues that are really important to the people affected by blood cancer, and reminds us about the impact our work can have on the lives of others'*.

ECSG is grateful to the University of York and Blood Cancer UK, who contributed towards this event, thereby enabling us to strengthen our involvement with people affected by blood cancer.



Patients with blood cancer and their relatives and friends congregating before the open day.



Debra Howell talks about ECSG's blood cancer research and the benefits of PPI.



John Dodds, a blood cancer patient who spoke about his experiences of lymphoma



Q&A with haematologists, researchers/scientists and a patient representative

## Patient engagement opportunity - for patients living in the Humber and North Yorkshire Cancer Alliance area

A new project is looking to engage with people who have been diagnosed with cancer within the last 5 years who have any pre-existing mental health conditions, whether diagnosed or self-identified.

The Treatment, Pathways and Personalised Care Team at the **Humber and North Yorkshire Cancer Alliance** are working with partners across Humber, York and North Yorkshire, to improve the psychological and emotional support available to people affected by cancer throughout their cancer diagnosis, treatment and recovery.

They want to work with individuals and/or small groups of people to discover what particular issues they have experienced and work with them to co-produce solutions to improve the access to psychological and emotional support for future patients.

### PHASE 1

Participants will

- share their story with us
- answer some questions about their experiences of psychological and social support after a cancer diagnosis

There is also the option to join our steering group to help guide and plan and implement this work

### PHASE 2

Once the engagement work is complete, participants will have the opportunity to work with the team to co-produce solutions to some of the most pressing issues, monitor the testing of ideas and evaluate the tests to make recommendations about next steps.

**RECRUITING PATIENTS WHO HAVE LIVED EXPERIENCE OF A PRE-EXISTING MENTAL HEALTH CONDITION AND A CANCER DIAGNOSIS**

(including self perceived mental health conditions)

For more information about the role please contact either:

Zoe Bounds – [zoe.bounds@nhs.net](mailto:zoe.bounds@nhs.net)  
(Tel: 07851 248073)

or

Karen Lindley – [karenlindley@nhs.net](mailto:karenlindley@nhs.net)  
(Tel: 07851 252430)





**The Project**

We are working with multiple organisations to improve access to psychosocial and emotional support for people with a pre-existing mental health conditions who have also received a cancer diagnosis.

We want to hear from people from a diverse range of backgrounds from all areas across the Humber and North Yorkshire footprint.

We want to hear your experiences in getting both psychological and emotional support (the good and the bad) so we can co-produce solutions to help improve access to this support for future patients.

**The Role**

**What does it involve:**  
Attending online meetings via Teams to advise on the suitability of content, methods and materials, from a patient perspective.

**Meeting Frequency:**  
Every 2 weeks (until March 2024 and possibly beyond)

**Meeting Duration:**  
1 hour meeting + reading time

**Payment:**  
Expenses will be paid as necessary.

**About You**

- Be willing to actively contribute to discussions in a way that is comfortable for you.
- Be willing to share your personal story and experiences about having any mental health condition (whether self-perceived or diagnosed) and a cancer diagnosis throughout diagnosis, treatment and recovery.
- Be willing to answer questions about the psychological and emotional support you did/did not receive.
- Be willing to familiarise yourself with relevant research, medical language and documents.

The team will make reasonable adjustments to ensure participants are made to feel at ease throughout all stages of the process and will interact with them wherever they feel comfortable; in person, online, over the phone or via email. They will also welcome support from mental health professionals where this is wanted or needed.

If you are interested in taking part, you can get in touch by telephone or email using the details below or ask a carer, friend, family member or professional to get in touch on your behalf. The closing date for registering interest is 15<sup>th</sup> December.

We look forward to hearing from you.

Zoe Bounds (pictured left)  
✉ [zoe.bounds@nhs.net](mailto:zoe.bounds@nhs.net) ☎ 07851 248073

Karen Lindley ✉ [karenlindley@nhs.net](mailto:karenlindley@nhs.net)  
☎ 07851 252430








**SAFEENA** is the first ever national Muslim Cancer Support Network in the UK to provide services specifically for Muslims affected by cancer. Although targeted at Muslims our services can be accessed by anyone, faith or no faith alike. Safeena MCSN is a free service, led by Muslims, for Muslims.

Cancer is indiscriminate, affecting people regardless of background, race or age. Despite the common occurrence of cancer, there is no targeted support for Muslims to address our specific cultural and religious needs. We provide practical, educational, emotional support, and in particular, Islamic guidance' for Muslims affected by cancer.

We also provide a befriending service connecting you with someone who will listen and support you and your loved ones through cancer. Our befriending service is made up of people who have experienced cancer first-hand. We understand the challenges, questions and concerns you and your loved ones may have. Through our shared experiences we can help you. Accessible via email & phone, befrienders are matched with you by gender, circumstances, and preferred language.

Contact us to find out more [www.safeena.org.uk](http://www.safeena.org.uk)



## New role for Louise

Louise Marley who has led Heads Together Head and Neck cancer support group in Sheffield for many years, now has a new role.

Louise has moved to Barnsley Hospital NHS Foundation Trust where she is a Macmillan Personalised Care facilitator. Her role will be to enable & empower health care professionals in both primary & acute care settings, to be able to fulfil their vital roles within the Personalised Cancer Care Agenda.

So patients can then receive more personalised, individualised care at all stages of their cancer journey. Improving at the same time care provision through better communication between the varied care sectors which aids a more seamless service.

She is very excited about her new role and the thought of being able to enhance care provision whilst working alongside and supporting staff delivering the care.

To contact Louise

✉ [Louise.marley@nhs.net](mailto:Louise.marley@nhs.net)

Louise worked alongside volunteer Eric Bailey to run the group which still meets at the Burton Street Project, Sheffield S6 2HH, every two months.

For further information about Heads Together contact clinical nurse specialists Tracy or Louise on ☎0114 226877.



Louise, third from the right

## Stories of Cancer and Hope

You may remember in our Summer edition we told you about author Kevin Donaghy who had brought together 39 stories from patients and their families about their experience of cancer.

IT worker Kevin, an ambassador for Melanoma UK, compiled the stories to bring hope and comfort to those living with cancer.

Kevin was diagnosed with stage two melanoma five years ago and was told the cancer hadn't spread. But in December 2019 back pain led to the discovery his illness had returned and was incurable. He described the diagnosis as "like a wrecking ball, everything just got smashed to pieces".

His cancer is now under control, but he wants to make sure others don't feel the sense of isolation and confusion he did. He compiled a book of stories from, and about, those who have experienced the disease.

He says: "The NHS is an amazing organisation for looking after you physically, but mentally you're looking for answers. It was through talking to other people that have experienced cancer that hope started to build. It got me to the point of thinking 'surely I'm not alone, surely other people are looking for the same sort of hope'".



Since then Kevin has appeared on numerous TV and radio shows talking about his collection of stories and even been a guest on our monthly online Support Group and Chat meeting. He has also been interviewed on Jacqui Drake's Cancer Journeys podcast on BCB Radio available on [www.yorkshirecancercommunity.co.uk/your-voice/#podcast/](http://www.yorkshirecancercommunity.co.uk/your-voice/#podcast/)

The book has captured the public imagination and now Kevin has ordered a second print run, made possible by an army of sponsors and friends. Books are donated to cancer charities and hospitals across the UK.



You can see Kevin being interviewed on Scottish TV here:

The video is available for your viewing pleasure at <https://vimeo.com/831495515>

To apply for a copy of Kevin's book ✉ [storiesofhopeandcancer@gmail.com](mailto:storiesofhopeandcancer@gmail.com)

Yorkshire Cancer Community Administrator Clare receives two more boxes of Kevin's book which we will give out to local support groups and individual patients.



# Taking the Cancer SMART message to communities in Yorkshire this Autumn



Joan visited our information stand in Beeston, Leeds, to chat to Cancer Champion Ric and pick up some leaflets for her voluntary work locally.

Every week in West Yorkshire, 225 people are diagnosed with cancer and 108 people lose their lives. Whenever we deliver those statistics to groups and individuals we are met with shocked silence.

That is why Cancer Champions are passionate about raising awareness – to help communities to know the signs and symptoms of cancer – to be aware, better informed, attend screenings and know where to go for help.

Cancer Champions are ordinary people – some have had a cancer diagnosis – some haven't – but all have one thing in common. To help get the Cancer SMART message to as many organisations, workplaces and community settings as possible.

Here is a roundup of just some of the places we have visited this Autumn, and it was lovely to get to events in Sheffield and Hull this time around.



We usually piggy back on other peoples' events, but we organised our own Health and Wellbeing Marketplace in partnership with community Arts Centre Chapel FM in Seacroft, Leeds. We had an amazing day with lots of visitors, stalls and delicious home-made food but the icing on the cake was the visit by the Lord Mayor of Leeds Cllr Al Garthwaite, and her consort, Alderwoman Angela Gabriel BEM. Here the Lord Mayor is seen chatting to Janet, a volunteer for Prostate Cancer UK.



Jill is seen with Fraser Corry, Macmillan Engagement Lead for West Yorkshire, Harrogate and South Yorkshire at a Health and Wellbeing event for head and neck cancer patients in Sheffield. The event was funded by Get-A-Head.





Eric Bailey who chairs Heads Together, head and neck cancer support group, who hosted the event at Sheffield United.



We've been visiting all the family support groups offered by **Home-Start Wakefield & District**, a charity which offers a network of trained volunteers and expert support to help families with young children through their challenging times. Here we have Emma (left) and Danni taking time out with Big Ted after a hectic session in Alverthorpe, Wakefield.



Ania, a volunteer for Wakefield & District Sightaid, is never seen without a smile on her face. Ania, who had a brain tumour as a child, is a blind artist who creates artwork from glass beads. We visited Sightaid's lively 'Demonstration day' to join with other information stands in Wakefield's Ridings Centre.



**Humber and North Yorkshire Cancer Alliance** invited us to their annual conference at the MKM Stadium, Hull, and we caught up with Martin, Wilf and Eddie from the Lincolnshire & Humber Prostate Cancer Support Group. It was great to see the guys in real life instead of zoom! At the same event - here's Zoe Bounds (below) from York Breast Friends – a former Yorkshire Cancer Community trustee.







The Crafty Creatives, a support group who meet in Outwood, Wakefield, multi tasked and made these amazing autumn wreaths while listening to the Cancer SMART presentation. The group are led by Claire Stewart (pictured 4<sup>th</sup> from the right), who was diagnosed with cervical cancer last year.



One of our newest Cancer Champions Phil, from Kam's Corner CIC, with author Mycil Muhammad, held a stall at our Health and Wellbeing Marketplace at The Huddersfield Mission. We had more than 18 organisations taking part with lots of good networking and information sharing.

Cancer Champions Gill and David are seen at the Mission. Gill, also volunteers for Ovacom, and David is a Yorkshire Cancer Community trustee and volunteer for Macmillan at Calderdale and Huddersfield hospitals.

